

Personally Speaking

All About People

Volume 1, Issue 3

DIVISION OF MENTAL RETARDATION SERVICES

September, 2005

The email came Thursday morning, September 1st to DMRS Assistant Commissioner for Administrative Services Fred Hix, three days after Hurricane Katrina marauded through the Gulf Coast. The message informed there were two mental retardation agencies from New Orleans resting at Fall Creek Falls State Park and looking for a home. The

New Orleans contingent shows its appreciation.



Mrs. Tiffany Berry, wife of Crossroads staff member Reginald Berry, with daughters Jasmine and Bria and their pooch Precious.



"One minute it was going here and one minute it was going there," said Carla Hood, Executive Director of Hood

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L to R: Don Wilson, Clover Bottom Asst. Superintendent for Administrative Services; Ron Specht, Crossroads Vocational Program Director; Steve Blair, Crossroads Program Director; Levi Harris, Clover Bottom Superintendent; Carla Hood, Hood Exec. Director; and Kathleen Clinton, DMRS Middle TN Regional Director.



DMRS Extends Hand to Two New Orleans MR Agencies



Evacuees buses arrive at Clover Bottom Developmental Center Tuesday, September 6th

ON ME



Children of Crossroads and Hood staff members play after arriving from Fall Creek Falls.



Clover Bottom Developmental Center workers prepare for their guests.

actions that followed inspire faith, foster goodwill and speak volumes to the resiliency of the evacuees and the professionalism, dedication and kindness of DMRS staff.

Staff at Crossroads of Louisiana, Inc. and Hood Management Group monitored an anemic Katrina following her deadly dance across Florida Thursday, August 25th,

killing eleven persons. Forecasts varied the next few days as the storm regained strength in the warm waters of the Gulf of Mexico.

Open Wide!

- DMRS and Hurricane Katrina
- New Law Aids Employment
- Pacesetters
- Legal Update
- Long and Winding Road
- Friends

Lean on Me...cont.

Management Group in New Orleans. "It kept getting stronger and finally we were told to evacuate. We have a standing emergency plan. Everything went smoothly and we were able to alert, organize, pack and put 120 people on the road in less than 24 hours."

The group was comprised of 40 persons with mental retardation and 80 agency staff and their families – plus one dog. Crossroads fled New Orleans last year as Hurricane Ivan threw it's temper tantrum, the agency settling at a state park in Monroe, Louisiana. As their two-bus caravan headed north Sunday, August 28th the agencies put out an all points bulletin to state parks across the Southeast.

"We worked the phones nonstop before we departed," said Crossroads Program Director Beverly Duncan. "A large group like we have and one with special needs, it's not too easy to secure accommodations. We had a good experience at a state park last year and explored those possibilities. Fortunately we lucked upon Fall Creek Falls."

DMRS: Rapid Deployment Force

As soon as Hix checked his email that Thursday morning, he contacted Assistant Commissioner for Facilities and Community Programs Larry Latham, who was traveling. Latham immediately called DMRS Middle Tennessee Regional Director Kathleen Clinton, who dispatched an intake team to Fall Creek Falls to meet with Crossroads and Hood officials. The next day those officials were at Clover Bottom Developmental Center conferring with Latham, Clinton, Clover Bottom Superintendent Levi Harris and members of his staff.

"It was decided Clover Bottom was the best place for the agencies and the persons they are supporting," said Clinton. "Thursday and Friday we were rushing to offer assistance and identify their needs. Our response was quick and well executed. However, that was only the beginning."

"Oh, man! We had work to do," said Harris. "Cleaning, painting, mopping, waxing, moving furniture, purchasing needed items – you name it, we did it. Our Housekeeping, Property, Procurement, Maintenance and

many other departments did extraordinary work getting ready for our guests. We burned the midnight oil that weekend preparing accommodations."

Welcome to Nashville

DMRS threw out the Welcome mat Tuesday, September 6th. Just before noon the buses rolled up at Clover Bottom with a covey of SUV escorts. As the persons being supported were settled in their rooms, staff families began acclimating to their surroundings. Children frolicked on the grounds, playing football and making use of the facility's swing sets and slides. The evacuated pooch, a Pomeranian named Precious darted among the youngsters. "We're very glad to be in Nashville," said



Tiffany Berry, wife of a Crossroads staffer, with her two young daughters and Precious. "It's nice to know what we're doing, can get settled and find out what happened to our lives in New Orleans. None of us know about our homes or anything."

"We're still coming to grips with everything," said Duncan. "Our possessions are what we managed to stuff in backpacks and gym bags before we left, along with items that have been donated. I can't stress enough the caring and hospitality shown by all Tennesseans since we arrived. It's helped so much to ease the trauma for many in our group. The Division of Mental Retardation Services is already like family."

What Now?

Several buildings at Clover Bottom are being utilized to house the DMRS guests. The gymnasium is being made available for day activities. The expected stay is several months, possibly until the first of the year. The plan is for the agencies to be self-sufficient, functioning just as they did in New Orleans with DMRS providing a healthy amount of assistance. DMRS Deputy Commissioner Stephen

Norris has attended cabinet meetings and sat in on conference calls, keeping Governor Phil Bredesen and Department of Finance and Administration Commissioner Dave Goetz apprised of the situation.

"We are here for our friends from New Orleans and will do whatever is necessary to make their stay as comfortable as possible and bring normality to their lives," said Norris. "This is a difficult time requiring a great deal of adjustment for those who have been displaced. Hurricane Katrina is one of the greatest tragedies in the history of our country. We look at this situation as an opportunity to help and will demonstrate the best DMRS has to offer."

For Crossroads and Hood the main focus right now is on the persons they support, getting everyone used to their surroundings and in a routine. In short order the task at hand will be shaking the cobwebs and lacing up the bootstraps; pointing their compass to the future. There are many unknowns and much to be done.

"We may be in retreat at the moment and some of us are still in shock, but make no mistake – we are determined," said Hood. "We will definitely go back. We will definitely rebuild. This is a chance to make a stronger, better New Orleans and we will. The wonderful support we're getting here in Tennessee cushions the blow and will make it easier to rebound. We'll come back stronger than ever."

Update as Personally Speaking goes to press: The acts of kindness and extraordinary effort to make our DMRS guests feel comfortable made by the Clover Bottom Developmental Center and Middle Tennessee Regional Office staffs has gone far and above the call of duty. Material and monetary donations, invitations into their homes, church, dinner, shopping and movies – the list goes on and on. The first week several Crossroads and Hood Management Group staff's children were assisted in enrolling in elementary and middle schools. A number of high school-age students will enroll soon. DMRS and the Nashville community are responding with unbridled enthusiasm and heartfelt care. ■

— HOW TO HELP —

TENNESSEE

The Tennessee Emergency Management Agency needs volunteers to help storm victims, but you must obtain storm credentials before heading to the disaster area. Contact TEMA at (615) 741-1496, (615) 741-0343 or 1-866-586-4483, or visit www.tnema.org.

The Red Cross needs shelter volunteers in the Nashville area. Contact Hands on Nashville at www.hon.org.

The Food Bank in Memphis is seeking nonperishable foods and personal care items, along with monetary contributions. Donations online at www.memphisfoodbank.org or send checks to: 239 S. Dudley, Memphis, TN 38104.

Volunteer Memphis needs persons to staff a phone bank for finding volunteers for Hurricane Katrina-related programs. Persons assisting need to be 18 or older. Contact Kevin Dean, 647-2850 or 523-2425.

The Community Foundation of Greater Memphis has a list of recommended agencies assisting victims of Hurricane Katrina. Go to www.cfgm.org.

To donate medical supplies or equipment, contact the Tennessee Department of Health, Emergency Medical Services at 1-800-778-4505 or (615) 741-6882.

NATIONALLY

American Red Cross
www.redcross.org
800-HELP-NOW

AmeriCares
www.americares.org
877-858-7788

Louisiana Disaster Recovery Foundation
www.louisianahelp.org
877-435-7521

Baton Rouge Area Foundation
www.braf.org
877-387-6126

Convoy of Hope
www.convoyofhope.org
417-823-8998

America's Second Harvest
www.secondharvest.org
800-771-2303

Catholic Charities
www.catholiccharitiesusa.org
800-919-9338



Humane Society of the United States
www.hsus.org
202-452-1100

American Humane Association
www.americanhumane.org
303-792-9900

LSU School of Veterinary Medicine
www.vetmed.lsu.edu
225-578-9900

Noah's Wish
www.noahswish.org
530-662-9317

American Veterinary Medical Foundation
www.avmf.org
800-248-2862, Ext. 6689

American Society for the Prevention of Cruelty to Animals
www.aspca.org
866-275-3923

Katrina Found Pets
www.katrinafoundpets.com

NEW LAW ASSISTS TENNESSEANS WITH DISABILITIES



Front Row L to R: Andrea Cooper, Asst. Comm., Div. of Rehabilitation Services; Virginia Trotter-Betts, Comm., Dept. of Mental Health and Developmental Disabilities; Senator Jim Bryson; Governor Phil Bredesen; Scott Finney, The Arc of Tennessee; Representative Harry Brooks; and Jason McAlexander, The Arc of Tennessee.

Back Row L to R: Stephen Norris, Deputy Comm., Div. of Mental Retardation Services; Dave Goetz, Comm., Dept. of Finance and Administration; Walter Rogers, Exec. Dir., The Arc of Tennessee; and Representative Jack Sharp.

Employment Opportunities Enhanced

Governor Phil Bredesen has signed into law a bill which provides incentives for Tennessee employers to hire, work with, train and mentor persons with disabilities who receive state services. The incentives are in the form of franchise and excise tax credits - \$5,000 for each new full-time employee and \$2,000 for each new part-time employee.

The credits apply to employers who hire persons served by the Division of Mental Retardation Services, Department of Mental Health and Developmental Disabilities, Department of Health, Division of Rehabilitation Services, Department of Finance and Administration and the Tennessee Committee for the Employment of Persons with Disabilities.

PACESETTERS

Setting the Pace on Supported Employment

In the late fall of 2003 the Executive Director and Leadership Team at Pacesetters began to significantly change the agency's approach to delivering supported employment services to our service recipients. Subsequent to considerable discussion and planning, the decision was made to create two positions as Job Developers for the agency. Prior to this time, the administrative duties of job development and supported employment had been handled by various staff members as a part of their day-to-day duties. The decision was made to hire the job developers, give them the support and latitude they needed to succeed, and not burden them with other responsibilities, to the point that they were to work from their homes rather than at the administrative office. One was hired in February of 2004, and the second a month later.

Both new Job Developers were subjected to the necessary agency orientation, training, and familiarization with the company policies, state regulations, and intra-agency communications and practices. At the same time they began the process of meeting and developing relationships with many of the individuals supported by the agency. Job Clubs began to meet, interviews with emphasis on career planning took place, and the momentum began to shift from a facilities based provider to a community based employment provider. It was during this period that word began to surface that the state was about to change the way agencies were to be compensated for delivering services to individuals.

After about six months and a few initial successes, the job developers met with the Administrative Leadership team and proposed that the agency further had the need for additional specialized support staff who were more directly involved with the individuals we were serving. At that time, our agency had centers in six counties in the Upper Cumberland and we were supporting about 215 individuals. From this meeting, a new staff position,



John Knox (left), Pacesetters Support Employment Specialist and Dr. Jeff Egelston, Pacesetters Executive Director.

Support Staff/Employment, or SSE was developed and funds were allocated to provide for four such positions immediately. The positions were posted, and the four positions were filled from existing support staff. After job coach training, these four were able to immediately make an impact in the success of our program. Soon to follow were two additional SSE positions and then later two additional 1/2 time positions, giving us presently a total of eight SSE staff persons in the now five counties where we have centers (one center closed in 2005). In August of 2005, one of the Job Developers moved out of the area and the remaining Job Developer has assumed administrative and supervisory responsibilities for the agency's supported employment team.

The benefits continue to become clearer each and every day.

- A young man who would hardly look at you a few months ago, and wouldn't try to speak at all, now waves across the room, anxious to tell you what's happening in his life.
- A man, who lives at home with his parents, decided that he wanted to work at his job in a local fast food restaurant on a holiday when the center was closed. From home, he called the manager himself, had his dad drop him off and pick him up, and didn't need staff at all that day. Before he started to work, his mom had told us we could never leave him alone.

- Three self-employed individuals are currently in the formative periods of developing their own businesses. An artist has sold a painting that is on display in an office in Washington, DC.
- About 2/3 through a recent meeting, an ISC turned to the lady who's meeting we were in and said, "I've known you for a long time and this the first meeting we've ever had for you that we didn't have to discuss money. Now that you're working, if you want something you can decide to buy it, and if folks are going out, you can chose to go, too, if you want to."
- Individuals are making new friends and forging new relationships with their co-workers, separate and apart from agency centers and activities.
- Incidences of "behavior problems" are declining as men and women are spending their time and energy working, observing co-workers, and realizing that their newfound independence is often all the attention they need.
- Employers and community people continue to be more and more receptive and supportive of people with disabilities as they interact more and more through working together.

Community employment wasn't new to Pacesetters. In February of 2004 when the Job Developers were hired, there were 33 individuals working in community employment, many of whom had several years' tenure at their jobs. With the expanded staff and attention on employment, the agency had 78 individuals working 89 different jobs by the end of 2004 (11 individuals worked more than one job). That was a total of 56 new jobs for 45 different individuals in calendar year 2004. The financial impact for the agency was positive due to the successful closure of 34 Vocational Rehab cases for FY 04-05. At that time about 37% of the individuals supported by the agency were participating in supported employment,

From the Desk of Deputy Commissioner Stephen H. Norris

In our nation's history books Hurricane Katrina is destined to be etched as one of America's worst natural disasters. The



deaths and enormity of destruction, pain and suffering is almost beyond comprehension. The storm ravaged the Gulf Coast and has shaken us with a fury not seen since 9/11.

New Orleans is basically destroyed. It will be well into October before water is drained from the city. Estimates are that it may possibly take years to rebuild. We watch on television, read the newspapers, view the internet and listen to the radio as the tragedy unfolds.

We are seeing a migration of displaced persons moving west and north. The exodus north is placing Tennessee as a primary landing spot for evacuees. This is one of the premiere moments in our state's history that we are afforded the opportunity to uphold our motto as the "Volunteer State."

Governor Bredesen is making Tennessee's resources readily available to the evacuees. The Governor has directed all areas of state government to make assisting the victims a top priority. He has worked to eliminate red tape so services can be rendered expeditiously. In his words, "We'll deal with dotting the i's and crossing the t's later."

I am pleased to tell you the Division of Mental Retardation Services has responded with great speed and caring in this time of crisis. On Thursday morning, September 1st we received word there were two New Orleans mental retardation agencies at Fall Creek Falls State Park looking for a home. Crossroads of Louisiana, Inc. and Hood Management Group fled the city on Sunday, August 28th, one day before the storm's onslaught. Forty service recipients and 80 staff members and their families, along with one dog boarded two buses bound for Tennessee.

Immediately upon notification DMRS Assistant Commissioner for Facilities and Community Services Larry Latham put in motion procedures to explore assistance. DMRS Middle Tennessee Regional Director Kathleen Clinton dispatched an intake team to Fall Creek Falls that afternoon. By the next afternoon Crossroads and Hood officials were sitting in Clover Bottom Developmental Center Superintendent Levi Harris's office finalizing plans to call Clover Bottom home.

I can not state enough the pride and admiration I have for the DMRS personnel who rallied to prepare Clover Bottom for the arrival and smooth transition of our guests. Levi Harris, Assistant Superintendent for Administrative Services Don Wilson, Director of Procurement Steve Blair, Kathleen Clinton and all their staff fashioned something just short of a miracle.

DMRS will serve as hosts for several months, probably stretching into the first of next year. This is a difficult time for our guests, having left home, not knowing the status of their lives there. Everyone at DMRS will work together, ramping up our efforts to make this the best possible experience for them. We offer a strong dose of hospitality, caring, commitment and

assistance wherever and whenever it is needed.

This is a time to demonstrate the professionalism and compassion I have seen so often since I assumed leadership of this division nearly two years ago. We will show our best at all times and provide our friends from New Orleans a base from which they can regroup and plan their future.

I have stated many times that serving as DMRS Deputy Commissioner is the most challenging position I have ever held. It is. And it is also the most satisfying. ■

Golfing for Autism Awareness

The Autism Society of Middle Tennessee (ASMT) is staging its first annual "Links for Autism Awareness" fundraising event October 10th at Greystone Golf Club in Dickson. The goal is to raise \$35,000 for the programs, services and support that the ASMT provides and to get the word out on the Autism community in Middle Tennessee.

Each foursome solicits friends, family and other associates to donate to ASMT. The team that raises the most funds receives a trip to Florida to play the Tournament Players Championship at Sawgrass course – one of the top courses in the country and home to two prominent pro tournaments.

There is over \$1,500 in prizes for the top scoring teams and three golfers get to shoot for a \$1 million dollar hole-in-one. Male or female, young or old, good or bad, all are invited to be part of the event. You don't even have to play golf to participate.

For more information contact:
ASMT President Dan Hayes
615-595-1664
hayesconsulting@comcast.net

David Low, Golf Tours of Tennessee
David@golftoursoftennessee.com ■

– L E G A L U P D A T E –

Several federal lawsuits have influenced the service system of DMRS over recent years. Each suit has specific orders and mandates that the division must follow. Below is the current status of each.

The Arlington Developmental Center Remedial Order (1993)

DMRS Deputy Commissioner Stephen Norris has announced DMRS's intention to close Arlington Developmental Center (ADC) over the next three to four years. The facility requires extensive repairs and remodeling costs would be significant. ADC's census, presently 180, has been slowly decreasing as more and more residents move to homes in the community.

Norris spoke to the Parent Guardian Association (PGA) of West Tennessee last month to explain how the State will work with them and others as persons transition to new homes. ADC residents have several housing options to choose from when they are ready to relocate, including supported living, personal assistance support, self-determination services, family model homes and others.

The lawsuit parties continue to negotiate a new agreement. It is the State's intent that this agreement should cover the issues previously agreed upon in both the 2001 Mediation Settlement Agreement (agreed to by all parties) and the 2004 Show Cause Agreement (agreed to by all parties except the PGA). The agreement may also include some details surrounding the planned closure of ADC.

The Clover Bottom and Greene Valley Development Center Settlement Agreement (1996)

No update.

Brown Waiting List Settlement (2004)

Last fiscal year (FY 2005 – July 2004 through June 2005) DMRS was able to enroll and initiate new services to seven hundred ninety-two (792) people from the statewide waiting list. Of these:

- 63 went directly to the Self-Determination Waiver
- 99 were provided Self-Determination Interim Supports
- 630 were enrolled directly in the statewide Home and Community Based Waiver

There was a total of \$2,456,975.42 spent on the new Consumer Directed Supports program. These funds are part of the Brown Settlement Agreement. Persons, who are on the waiting list in the Crisis, Urgent or Active categories and who do not receive Family Support funds are eligible.

So far this fiscal year (FY 2006), there have been a total of 158 persons enrolled into services from the waiting list. IN addition, a total of \$220,328 was spent on the Consumer Directed Supports program during the month of July.

As a reminder, please keep in contact with your assigned case manager and regional office. If you situation or circumstances change, please make sure your case manager is aware, as it may impact your assigned category of need (Crisis, Urgent, Active or Deferred) status. ■

Pacesetters...cont.

which was some twelve percentage points above the state's target of 25% for the end of the year. As 05-06 began there were approximately 20 open VR cases, most moving smoothly along the timeline toward closure. Additionally, there are almost 50 new individuals that have expressed an interest in community employment, and several of these 50 already having employment included in their ISP. Job exploration, Job Club, and other related employment activities are ongoing events in each of our centers.

In retrospect there are several factors that have and are contributing to the recent success of Pacesetters' supported employment. Following are some of those:

- The commitment by the agency leadership to administrative staff positions whose total focus is on employment
- The opportunity to utilize seasoned and trained Direct Support employees to fill the newly created SSE positions
- The attitudes of community employers willing to consider an individual's potential instead of his limitations
- The willingness of the men and women we support to step outside their comfort zones into the community to try some new and sometimes challenging jobs in an environment that often is as unsure as they are
- The support and encouragement of family members and home staff personnel who do so many of the behind the scenes things to prepare an individual to be ready to get to work
- The excitement generated and exhibited by those who are working-a very positive kind of peer pressure, or peer modeling
- The support of Benefits Counselors, DRS counselors, ISC's, therapist, and other team members, many of whom are forever in the background, but continuously influencing the success of this program
- The inclusion by the agency of Job Coach training as part of core training for all Direct Support Staff, to enable the agency to always be able to support individuals on the job, even if the SSE were to be unavailable
- The opportunity to be a part of MTEC and the Tennessee Employment Consortium's monthly meetings as a forum for exchanging ideas and mutual support with other providers and agencies.
- The additional funding made available through a grant provided by TEC that helped offset many of the costs involved in starting and administering our

Up Close and Personal



Shirley Stephenson, 1967



Shirley Stephenson,
Greene Valley
Developmental
Center Program
Director

The Long and Winding Road

Shirley Stephenson's Triumphant Tenure at Greene Valley

The Soviets built the Berlin Wall. Roger Maris belted 61 homeruns to break Babe Ruth's single-season record. Everyone liked to "Sing Along with Mitch" and wonder about the location of "Car 54." Barbie got a new boyfriend.

In 1961 Shirley Stephenson was fashioning flower arrangements with her best friend at a Greeneville florist. The ladies' careers weren't exactly blossoming. The friend's brother served as a security officer at Greene Valley Developmental Center. He encouraged the ladies to "Stop and smell the roses" at the center. A career was seeded.

"I said, 'What the heck, I'll give it a try,'" Stephenson recalled smilingly. "When I started I thought I'd work a year or two and then move on. However, after a few months my thinking changed. I got attached to the people I was helping. I began to develop a strong feeling of self-worth and satisfaction. Soon I was arriving at work determined to make that day better than the one before for our residents."

Stephenson's original one or two-year plan morphed into an Energizer Bunny-like 44 year agenda – and she's still going strong! Her current title is Institutional Program Director, overseeing two residential homes. Her responsibilities are: To insure the residents are protected from harm, abuse, mistreatment and neglect; that there are supports in place to assist them in leading the best possible independent lives; and to provide her staff with the necessary training to perform their task, offer them

opportunities for growth and provide a safe work environment.

"Shirley is a bright, shining light," said Greene Valley Developmental Center Superintendent Henry Meece. "It is not possible to adequately state all the good things she has done and the difference she has made at Greene Valley. Our center and DMRS have been very fortunate to have had Shirley's services all these years and hopefully we will have her for some time to come. She is truly a very special person."

In the early 1960s Greene Valley was an austere operation. Stephenson says advances in medicine and monies for staffing and equipment have been the greatest advances.

Through the years she has worked as a psychiatric aide, charge aide, supervisor and wrote self-help programs. When she started work her salary was \$160 a month. Any service training was on her days off and she received no compensation. She received much of her education through "hands on" experience. At times "learning the ropes" could be an adventure.

"When I first started I spent some time working in the infirmary," said Stephenson. "One day a resident was brought in with bad cuts from a broken window; he was bleeding profusely. I was assisting a Registered Nurse. She told me to go get a couple of 4 X 4's. It was frenzied and I'm thinking, 'What are we going to do? Knock him out? Do we have a lumber yard?' The nurse was talking about bandages. Right then I learned never hesitate to ask questions!"

Stephenson says that when she retires she'll miss terribly her co-workers and of course the persons she supports. There is a

"protectiveness" where she is concerned regarding the residents. They must be cared for in the best possible way, utilizing the highest standards.

No one is rushing Stephenson out the door and she's not even thinking about reaching for the knob. Retirement is out there circling somewhere, but it hasn't blipped on her radar screen yet.

"One day will come along and I'll know it's time," said Stephenson. "I love what I do and am enjoying life. I know I can make a difference in the lives of our residents. Why stop?" ■

Pacesetters...cont.

Supported Employment program for FY 04-05.

Our crystal ball is a little blurred right now and we aren't certain what may be next. We do believe, however, that the men and women in our program are experiencing newfound growth, increased confidence, and independence by participating in community employment. We are seeing positive steps being made toward "normalization" for many. Realistically, we understand that everyone may not be a candidate for working in the community for any of a number of reasons. For others, the time may not be right. Our attention remains focused on those who have expressed an interest in working, whose plan calls for it, and who have the potential supports in place to make it happen. We remain focused on the goal, but continue to be flexible enough to respond to changing circumstances, regulations, and the needs of the individuals we support. To that end, our expectation is that we will continue to experience varying degrees of success in the months and years ahead. ■

Medical Message

Dr. Adadot Hayes, M.D., DMRS Medical Director

Clinical Needs for Persons with Mental Retardation

Although people with mental retardation have the same acute medical problems as the rest of the population, the majority of their problems relate to chronic issues which begin early in life, often at birth. People with mental retardation, by definition, have an abnormal brain which also contributes to difficulties in behavior (originating in the brain) and problems with physical status (since muscles are innervated by nerves which come from the brain) and may affect both use and appearance.

Individuals with mental retardation, over the span of their lifetime, learn to adapt to these disabilities and we need to help them maximize their abilities by appropriate clinical treatment. These problems are often viewed by the general population as chronic "non-curable" problems. Because of their lack of communicative abilities (either because they don't speak or don't express themselves well), many people with MR also pose problems in dealing with the clinical world in defining and treating their medical problems. In addition, there are many misconceptions about people with mental retardation relating to their ability to enjoy life, their ability to have emotions, their life span and in particular concern about their behavior or what their behaviors mean.

People with mental retardation generally have disabilities beyond those seen in the general population which fall into three distinct areas, often not considered in traditional clinical settings. These include cognitive abilities, physical abilities, and neurobehavioral strategies. An example of the impact of cognitive deficits (MR) on health and well-being would be someone who is unable to talk and would have difficulty explaining symptoms to a physician. In addition, they would have associated problems related to following



*Dr. Adadot Hayes, M.D.
DMRS Medical Director*

through with healthcare recommendations. As such, DMRS strategizes to support these needs.

In the physical area, many of our service recipients have difficulties with normal positioning or movement which may impact another activity such as eating or gross motor activity such as sitting and walking and fine motor activity such as hand use (i.e. writing, buttoning, zipping.)

Most people are familiar with traditional therapies when a person has an injury. So, for instance, if someone breaks a leg they may need short term physical therapy to learn to walk again after healing. If someone has a stroke, they may receive speech therapy to help them speak again and occupational therapy to help them rehabilitate back to their prior abilities for normal functions of daily living. For the most part, these therapies are short term and when people complete their goals or stop making progress, these services are discontinued.

In people with mental retardation and developmental disabilities, the goals are often somewhat different and may relate to maintenance or promoting function or showing gains in new abilities. For example, someone who is developing or has scoliosis or contractures of their joints might benefit from ongoing therapy and positioning to prevent progression of these problems which could result in significant medical issues such as respiratory problems, fractures, or pain.

In addition, some therapies allow continuation of routine activities of daily living which may contribute to overall health. An example of this would be someone who has difficulty self-feeding or chewing and problems maintaining an upright position for eating. Maintaining as much independence for eating, in a person such as this, would contribute not only to well-being and self-image but also to decreased health problems. As an example, many people who have eating problems such as swallowing and chewing can benefit from development of a dining plan with specialized equipment and specialized procedures which allow them to continue feeding without the risk of choking and subsequent pneumonia.

Some individuals who do not have swallowing problems may benefit from therapies allowing them to use their hands in use of feeding themselves to maintain independence. In addition, sometimes positioning alone will make choking better and also contribute to decreased chronic constipation which can lead to obstruction, surgical emergencies and death. These sorts of therapies require specialized training and specialized evaluations which often do not fit into routine short term therapy that most of the rest of the population may occasionally require.

Individuals with mental retardation in our system also occasionally need some specialized nursing to integrate their medical treatments or for specialized treatments. As an example of the latter, we have many people who are fed by enteral feeding tubes. These tubes are not placed because people are in a terminal state, as most of the general population is familiar with, but because for some reason, perhaps a swallowing problem or chronic pneumonia, individuals are unable to eat by mouth. Many individuals with feeding tubes go on to live productive, happy lives functioning at their level for many years after placement of the tube. However, having a tube requires nursing oversight for feeding regimens as well as awareness of potential medical problems and emergencies.

We also have many people with mental retardation in our service system who have

Medical Message...cont.

multiple and sometimes unusual combinations of medical problems. It is not uncommon to have a service recipient who has seizures, gastro-intestinal problems (such as GE reflux disease and constipation), osteoporosis, respiratory problems, spasticity requiring medication and on many occasions behavior problems requiring psychotropic medications. Oversight of these complicated, medically-complex people requires nursing oversight by individuals who understand these often unusual problems.

People with mental retardation often have problems with behavior based on their lack of coping ability or control of situations. These are usually not related to an underlying psychiatric problem but are often a means of communication or expression of emotions. Within our service system, we have professionals who utilize formats for addressing behavior that is the result of these situations and is not related to psychiatric problems. This is somewhat unique in our field and is necessary to avoid inappropriately over medicating with behavior medications which could lead to complicated medical side-effects. To achieve this goal, we have people with specialized training in behavioral areas. This is often not present in other service sectors such as the mental health system and often not required or utilized by the general population.

In addition, we often have rather significant medical challenges in the people in our service system. This requires integration of clinical support among all of our clinicians and support of agencies that support our service recipients. Some of these issues might involve something as simple as modifications to obtain routine preventive care which is available to the rest of us. It also might involve monitoring of seemingly minor problems in the rest of the population such as constipation.

For example in the general population, although most everybody has experienced constipation, it usually resolves and would include either the person treating himself

or seeking professional treatment early. With our population, particularly those who are non-verbal, constipation is a major problem. This population is at very high risk. They often have predisposing factors such as decreased activity, decreased access to free fluids, have had chronic long term constipation and often are on medications that might contribute to constipation. This is an often overlooked problem that the clinicians with DMRS oversee quite diligently to prevent such outcomes as obstruction requiring surgery and negative outcomes such as death.

Other challenges created by the population that we serve are a lack of medical history and medical information. Many people in our system have been to a variety of doctors and a variety of settings with a lack of transfer of information. The department supports strategies to attempt to avoid this. In addition, often people with mental retardation have unusual presentations of common problems because of their inability to either speak or express themselves. For instance, GE reflux (heartburn) is a very common finding in the general population. Most people either treat themselves by going to the local drug store or will present themselves to a physician and outline their problems after which they generally receive adequate treatment.

In our population, since people are non-verbal and since the problems are internal the early symptoms of heartburn are often missed because the person cannot indicate discomfort. Therefore, their problems are not recognized until later when they have secondary problems such as anemia or bleeding. In addition, particularly in people who are non-verbal, this sort of discomfort often creates behavior such as sleep problems, irritability, aggression or change in activity which needs to be interpreted in a different way compared to someone who does not have a disability. DMRS provides strategies and education to try to avoid these problems.

Other challenges with supporting medical issues in this population relate to challenges of monitoring both the effect

and side-effects of medications. For example, the side-effects of many seizure medications which are often used in this population are such symptoms as pain, dizziness or nausea which are difficult to observe in a non-verbal population. This requires other indirect methods to assess this. In addition, among this population we have many people with very rare low incidence genetic diagnoses which may also have as part of their components unrecognized medical problems. This requires understanding of the entire person and integration of the genetic diagnosis which might provide a road map for medical care.

For example, people with Down Syndrome have very well defined medical problems which are easily diagnosed and treated if they are anticipated. An example is hypothyroidism which occurs in a high percentage of people with Down Syndrome and increases with age. This leads to obesity (not an expected finding for Down Syndrome), decreased activity and, in severe cases, bradycardia (slow heartbeat) which would be misinterpreted as a heart problem. Having the knowledge to look for this contributes to early diagnoses and treatment and prevents significant discomfort and complications.

Because of all these issues, DMRS has clinicians involved in promoting strategies for education, monitoring and consultation to promote specialized clinical care for service recipients. These services are usually provided in the private sector and are paid for by Medicaid funds (under a "waiver program") or state funds.

DMRS also supports and promotes the use of other clinical services routinely used by the rest of the population. The bottom line is that people with mental retardation have the same clinical problems and need the same treatment as the general population but because of their unique disabilities they may need special understanding or modification of routine services. ■

F • R • I • E • N • D • S



The ARC, Membership and You

The Arc of Tennessee is a non-profit, family-based, membership organization dedicated to people with mental retardation and related disabilities. For over 50 years The Arc has been creating choices for individuals. We value diversity and manage our organization through these values: Integrity, Courage, Respect and Justice.

Why belong to The Arc?

- Because disability touches your life in ways you never expected!
- Because families who live with disability understand each other!
- Because some disabilities don't go away - some people will always need a bit or a lot of help - The Arc helps families find a way to live with ongoing disabilities.
- Because you are a self-advocate and want to be as self-sufficient as you can be.
- Because it is lonely out there alone.
- Because you want systems you can count on for those things you can't do yourself!
- Because people who have disabilities are great teachers - if we listen.
- Because some people who don't live with disability still don't "get it."
- Because you are a professional and you want to stand by families.
- Because there is strength in numbers and

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T E N N E S S E E D I S A B I L I T Y C O A L I T I O N

Battling for the Ballot Box

The right to vote is a foundational element of our democracy that can



only be denied to individuals in extremely rare circumstances. This was recognized by the Supreme Court in the 1964 case *Wesberry v. Sanders*, "No right is more precious in a free country than that of having a voice in the election of those who make the laws under which, as good citizens, we must live."

That is why the Tennessee Disability Coalition's VOTE! Campaign is looking forward to its fourth year of fighting for and empowering individuals with disabilities at the ballot box. Our past efforts include voter registration drives; get out the vote campaigns, voter education initiatives and polling place accessibility projects as well as meetings with state and local election officials.

These efforts have been bolstered by legislation such as the Americans with Disabilities Act (ADA), the Help America Vote Act (HAVA) and the National Voter Right's Act (NVRA). Such legislation combined with technological advances has made polling places more accessibility for

cont. page 11

T E N N E S S E E C O U N C I L



DEVELOPMENTAL DISABILITIES

Council Youth Leadership Forum Graduates Impressive Class in 2005

Twenty high school students from across Tennessee graduated from the Council's Youth Leadership Forum in June 2005. The students met on the Vanderbilt

University campus for four days of leadership training, fun and sessions



on college resources for students with disabilities, being prepared for employment, assistive technology and the history of the disability experience. It was a very diverse class, with several kids who we will definitely be hearing good things about in the future!

The Youth Leadership Forum depends on a tremendous amount of help from volunteers from across the state.

cont. page 11

The ARC...cont.

we need strength.

- Because there is a lot of work to do and The Arc is effective.
- Because in a democracy, citizen action is the only answer.
- Because you need The Arc and The Arc needs YOU!

What are a few benefits I will receive when I am a member?

- By joining any local chapter of The Arc, you will automatically become a member of The Arc of Tennessee and The Arc of the United States.
- You will receive newsletters - The Arc Connection, The Legislative Monitor, The Arc Insight and other publications.
- You will have the opportunity to be involved in your local chapter in your own community to meet others who have shared or will be sharing similar experiences.
- You will become informed through support group meetings and have the opportunity to help others.
- You can participate in trainings in self-determination, self-advocacy and choice, new agency start-up and how our system works.
- You can have direct input into government processes by serving on advisory boards, workgroups and committees.
- You will receive legislative alerts when disability issues, bills and laws are on the forefront.

For more information on The Arc and becoming a member, visit our website at www.thearctn.org, send an email to info@thearctn.org, or call 1-800-835-7077. ■

TDC ...cont.

individuals with physical disabilities; however, individuals with cognitive and developmental challenges continue to face needless barriers at the ballot box.

In fact, it is not unusual for such individuals to be questioned by election officials about their ability to reason or comprehend the issues and candidates on the ballot. The motive behind an election officer's pop-quiz may be a well-meaning attempt to ensure that someone is not unduly influencing a person with a cognitive or developmental disorder, but such questioning is not sanctioned by any law in Tennessee. In fact, the voter qualifications set forth in the Tennessee Code are simple and straightforward: "A citizen of the United States (18) years of age or older who is a resident of this state is a qualified voter unless the citizen is disqualified under the provisions of this title or under a judgment of infamy pursuant to § 40-20-112."

This means that in Tennessee you have a right to vote if you are eighteen years old, have complied with registration requirements and have not committed a serious crime that resulted in revocation of your voting rights. There are no provisions in Tennessee law that requires a registered voter, even one with a conservator, to demonstrate some arbitrary level of cognitive function in order to vote.

If you have encountered problems at a polling place then contact the state Division of Elections at (615) 741-7956 or on the web at www.tennessee.gov/sos/election. Here you will find information about voting procedures such as absentee ballots, registration deadlines and links to your county election commissioner's office.

You can also contact Vote! Campaign Coordinator Joanne Rich at the Tennessee Disability Coalition for additional information regarding voter rights and information about participating in the VOTE! Campaign. Joanne's number is (615) 383-9442. ■

Tennessee Council...cont.

Counselors and mentors gave lots of time, energy and heart to this program.

Know of high school juniors and seniors who might be interested in participating in the Youth Leadership Forum in June 2006? Refer them to the Council office (615-532-6615 or tnddc@state.tn.us), or directly to Ned Solomon at 615-532-6556 or ned.solomon@state.tn.us. ■

NEW LAW...cont.

According to a 1998 National Organization on Disability (NOD)/Harris Poll of Americans with disabilities, large gaps exist between adults with disabilities and other adults regarding basic aspects of life. Employment was exposed as the widest chasm.

"This is a strong measure which will improve the lives of countless Tennesseans with disabilities," said Division of Mental Retardation Services Deputy Commissioner Stephen H. Norris. "Most persons with disabilities are able to work and are successful in all areas of our economy. Access to jobs affords them the opportunity to realize their dreams and be productive members of their communities."

State Representative Harry Brooks initiated discussion on employment incentives three years ago. While the law coming to fruition was a strong bi-partisan effort, it was Brooks and State Senator Jim Bryson who spearheaded the effort.

"I'm pleased to support legislation that will create an environment that improves the lives of our disabled citizens," said Brooks. "I believe our state can be a leader in fostering employment for persons with disabilities. This is a great step in that direction."

"This program creates a win-win situation," said Bryson. "It elevates self-worth and self-sufficiency; helping persons achieve life goals. It is also economically advantageous as there is relief from services, saving taxpayers money." ■



There are many acronyms and terms associated with the DMRS. In each issue of Personally Speaking we'll serve up a small portion of Division alphabet soup.

- **AAMR** **American Association of Mental Retardation**
- **PT** **Physical Therapy**
- **SDW** **Self Determination Waiver**
- **TEIS** **Tennessee Early Intervention System**

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Personally Speaking Listens!

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Got ideas or opinions? Send them our way!

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